

**PRIMARY CARE MANAGEMENT OF CHILDHOOD ASTHMA: ADDRESSING
CAREGIVER QUALITY OF LIFE USING ASTHMA ACTION PLANS WITH
PRESCHOOL-AGED CHILDREN**

by

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PROJECT SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR
THE DEGREE OF MASTER OF SCIENCE IN NURSING – FAMILY NURSE
PRACTITIONER

UNIVERSITY OF NORTHERN BRITISH COLUMBIA

August 2016

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Abstract

As the leading chronic disease in children both worldwide and in Canada, the care and management of paediatric asthma requires a significant amount of attention within health care delivery and research. While these efforts have typically been directed at the affected children themselves, or at improving the economic burden of this disease, there is substantial literature describing the effects childhood asthma can have on caregivers and their overall quality of life (QOL). Because of the high level of caregiver dependency among young children, such as preschoolers, it is clear that this effect is amplified with asthma in this age group. Current guidelines stress the use of asthma action plans (AAPs) to improve asthma outcomes in children, however there are few studies describing whether these tools may effect caregiver QOL. The purpose of this project is to evaluate whether AAPs used in the primary care setting can contribute to improved QOL in caregivers of preschool-aged children with asthma. Using an integrative literature review approach, I conducted a thorough analysis of the literature on asthma in preschoolers, the caregiver experience of childhood asthma, the primary care management of childhood asthma, and the use of AAPs in paediatric asthma. The information obtained validates the hypothesis that AAPs are valuable tools for promoting caregiver QOL in preschool-aged asthma. I close this paper by reviewing recommendations for implementing AAPs and other interventions aimed at caregiver QOL, along with suggestions for future research on this important topic.

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Acknowledgement

My sincerest appreciation goes to my advisory committee members, Linda Van Pelt, MScN, NP-F, and Amy Klepetar, BA, BScN, MScPH. Thank you both for the dedication and support you have provided throughout this process, despite juggling many other commitments in your lives. Your feedback and encouragement has played a major role in keeping me on track and pushing me to complete this project within the aimed timeline.

Dedication

This project is dedicated to the many people who have provided support and encouragement as I have worked towards completion of this degree. First and foremost, to Rob, whose unwavering support, love, and humour have kept me standing over the last two years. To my family and friends, my own personal cheer section since day one, for your constant confidence in me, and for being so understanding of my absence while I pursue this goal. Particularly, to my incredible parents, whose hard work and unconditional love have provided me the opportunities to get where I am today. To the UNBC faculty, and to my clinical preceptors Amber Reynolds, Chantel Canessa, Dr. Clair Biglow, Rosemary Cashman, Natalie Manhard, and Colleen Regehr for providing me with exceptional learning environments. And finally, to my classmates, who I cannot thank enough for the laughs, the tears, and the friendship through these last few years.

Chapter One

Introduction

Asthma is a highly prevalent chronic disease experienced by people of all demographics worldwide. It is estimated that 235 million people in the world have asthma, causing significant burden on individuals, families, and health systems, and making it one of the most common non-communicable diseases (World Health Organization, 2013). While childhood asthma is not a different disease than asthma in adults, it presents unique challenges both physiologically and in terms of approach to management. Most notably, as with any paediatric illness, the presence and involvement of the family may be exaggerated from that of an adult.

In my practice as an acute care paediatric registered nurse, I have seen first-hand the negative impact acute asthma exacerbations have on families—and particularly the caregivers—of children with asthma. I can recall many caregivers describing significant emotional stress as a result of their child's health concerns. As I move into a role based in primary care, this observation has led me to consider whether this impact on emotional well-being is situational and limited to hospitalizations and acute exacerbations, or whether it transfers to the everyday life of having a child with asthma.

Most individuals with asthma are treated in the primary care setting. A study by the American College of Allergy, Asthma & Immunology (2015) found that 64% of study participants with asthma were being treated by a primary care provider. As most nurse practitioners in BC work in primary care, it can be assumed that many have some level of involvement in the management of asthma in children. As such, I believe that primary care providers, including nurse practitioners, are in a position to address the concerns of stress and well-being in the caregivers of children with asthma.

My preliminary literature search for this project aimed at gathering information on the caregiver experience of having a child with asthma, reviewing current primary care management strategies and guidelines, and identifying barriers to care. From this initial review, I found that concerns regarding the well-being of caregivers extend well beyond the context of acute exacerbations and hospitalizations; effect on overall caregiver quality of life (QOL) is a well-documented problem in paediatric asthma, particularly with younger children such as preschoolers. Also standing out in this initial review, was the literature supporting the use of asthma action plans (AAPs) to improve asthma outcomes. Thus, I developed the following question to guide my research: “Can nurse practitioners, as primary care providers, use asthma action plans to improve the quality of life in the caregivers of preschool-aged children with asthma?” For the purpose of this paper, I will define “preschool-aged” as children between the ages of one and five, based on the ages designated by the Canadian Thoracic Society (CTS) guideline (Lougheed et al., 2012).

I hypothesize that the use of AAPs in this context would contribute to improved quality of life in caregivers. In this paper, I aim to link together current literature available on caregiver QOL, asthma in preschoolers, the primary care/NP role in asthma care, and the use of asthma action plans in order to evaluate this hypothesis and further explore this topic. I will carry this out using an integrative literature review format.

Chapter Two of this paper addresses the background and context relevant to the topic by breaking down the research question into each of its elements. This includes further exploration of childhood asthma, the caregiver experience of having a child with asthma, current considerations for caregiver QOL in the primary care management of asthma, and the use of asthma action plans in the management of childhood asthma. Chapter three outlines the approach

to this project, describing the literature review methods. Chapter four provides the findings from the critical analysis and evidence synthesis of the literature. This section identifies themes found to address the research question. Finally, chapter five provides a discussion of the findings, including implications and recommendations for the primary care management of childhood asthma.

Chapter Two

Background and Context

Beyond being a major chronic disease across all demographics worldwide, asthma is the most common chronic disease in children, affecting 14% of children globally (Global Asthma Network, 2014), and 10% of children ages 2 to 7 in Canada (Statistics Canada, 2010). With prevalence this high, it is perhaps not surprising that major implications are seen in terms of supporting the care of this disease. In Canada, asthma is the leading cause of hospitalization in children (Ortiz-Alvarez & Mikrogianakis, 2012), and is estimated to cost over 1 billion dollars annually in combined direct and indirect expenses (Asthma Society of Canada, 2014). Consequently, research and major task forces are often focused on end-point results of decreasing this economic burden. Thus, asthma in children continues to be well-researched in terms of etiology, effective management, and treatment to decrease exacerbations and hospitalization. However, the reality for those dealing with this disease, and those involved in its management, stretch beyond the biomedical and economical concerns that arise. The medical burden, along with the psychological and emotional impact of asthma have substantial effects on quality of life (QOL) for both children with asthma and their families (Carpenter et al., 2013).

As asthma is so common, it may be assumed that many primary care practitioners will be involved in the management of this disease. Practitioners involved in the management of asthma have a big task at hand; not only can these providers have an effect on the symptomatic management of the disease, but can also contribute to improving the quality of life in these children and their families.

Asthma in Preschoolers: Presentation, Pathophysiology, and Diagnostic Criteria

Asthma is a chronic respiratory disease characterized by airway hypersensitivity, intermittent or persistent airway inflammation, and resultant airflow limitations (Chesnutt & Prendergast, 2015). It is associated with variable degrees of dyspnea, wheezing, cough, chest tightness, and sputum production, from a variety of both endogenous and exogenous factors (Lougheed et al., 2012). With over 100 genes identified as playing a role in asthma risk and development, the disease is often familial in nature, but may also be influenced by allergen exposure, urban residence, air pollution exposure, exposure to tobacco smoke, recurrent respiratory infections, esophageal reflux, and obesity (Brashers & Huether, 2014a). The pathophysiology of what occurs during an acute asthma response relates to an immune hyperresponse to an antigen (i.e. an allergen). The antigen binds with IgE to mast cells, leading to mast cell degranulation and the release of inflammatory mediators, such as histamine. These mediators induce bronchospasm, airway edema, and mucus secretion from goblet cells. In addition, the activation of eosinophils produces proteins that contribute to damaging the respiratory epithelium, leading to further inflammation (Brashers & Huether, 2014a).

Though it affects individuals of all ages, asthma is highly prevalent in children, with highest incidence occurring during preschool age (1-5 years old) (Ducharme et al., 2015). Consequently, asthma is often viewed predominantly as a childhood disease. The pathophysiology of asthma in children is similar to that of an adult, however young children often present with more severe symptoms, and can deteriorate more quickly due to the smaller diameter of their airways, which puts them at a higher risk for obstruction (Brashers & Huether, 2014b).

Diagnostic criteria for asthma involves assessment of clinical presentation and spirometry, response to treatment, and consideration of risk factors. In preschoolers however, diagnosis can

be particularly challenging due to other respiratory conditions that may mimic asthma, such as recurrent bronchiolitis or croup, and the difficulty in obtaining spirometry. This often leads to a vague diagnosis, and inconsistent treatment of symptoms (Ducharme et al., 2015). The Canadian Thoracic Society (CTS) has therefore developed operational criteria for diagnosing asthma in this age group, with the aim of clarifying diagnoses, and guiding early treatment of symptoms (Ducharme et al.). The CTS operational diagnostic criteria for asthma in children 1 to 5 years of age requires:

- Either recurrent asthma-like symptoms or exacerbations, and
- Documented airflow obstruction, with wheeze being the most specific symptom, and
- Documented reversible airflow obstruction with short acting-beta agonist and/or oral corticosteroid, and
- No evidence of alternative diagnosis
- Heightened suspicion if personal atopy is present or with family history of asthma (though not required for diagnosis)

Asthma severity is generally categorized into four classes: intermittent, mild persistent, moderate persistent, and severe persistent. Current CTS Guidelines (Ducharme et al.) assume this classification for preschool children as well, while acknowledging that this age group experiences high individual variability in severity.

Treatment for asthma in preschool-aged children is primarily based on symptoms and severity and includes both pharmacological and non-pharmacological approaches.

Pharmacological interventions generally begin with as-needed doses of an inhaled short-acting β_2 -agonist for intermittent symptoms, with the addition of an inhaled corticosteroid taken daily at the lowest effective dose for persistent symptoms (Ducharme et al., 2015). Recommended non-

pharmacological interventions include asthma education, including a written AAP, avoidance of triggers, and reassessment every 3-4 months (Ducharme et al.)

The Caregiver Experience

Literature on childhood asthma is highly focused on the pharmacological treatment and management of symptoms. Though caregiver QOL has been reasonably addressed within this context, it is often assumed that asthma control is the only indicator of quality of life in the families of children with asthma. Asthma can present multiple challenges to the family of the affected child that have the potential to affect QOL.

As asthma management often requires daily interventions, the majority of care for this disease occurs in the home. As children are often dependent on their caregivers for even general activities of daily living, it is perhaps not surprising that responsibility for day-to-day management of asthma falls on them, causing significant effects on their lives. Major indicators for QOL in parents may include feelings associated with the burden of management (e.g. decision-making, medication administration, hospitalization), stress due to fears about the child's current and future health, and the stress due to consequences on the caregivers' ability to carry out work and household responsibilities (Bellin et al., 2013; Carpenter et al., 2013; Clark & Chalmers, 2003; Kieckhefer & Ratcliffe, 2000). The Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) is a tool developed by Juniper et al. (1996) that is used internationally to measure QOL in caregivers based on indicators of disease interference on normal daily life. The PACQLQ indicators (see Appendix B) will be maintained when describing quality of life in this paper.

I will focus specifically on the caregivers of preschool-aged children ages 1-5 with asthma in this paper because this population presents with unique challenges in terms of the indicators for

QOL. Foremost, preschool-aged children are highly dependent on their caregivers for all aspects of their care. This results in caregivers assuming the full burden of asthma management, whereas an older child is often able participate in a degree of self-management. Additionally, at this age, children and their caregivers are often dealing with a new diagnosis of asthma and the added stressors associated with this new diagnosis. According to Clark and Chalmers (2003), these may include stressors such as learning basic asthma management for their child, fear of the unknown, and the perceived lifestyle changes following diagnosis. Finally, asthma in this age group is associated with the highest rate of hospitalization, as well as high individual variability in severity, requiring frequent treatment adjustments by health providers. Consequently, it is not surprising that caregivers of preschool-aged children with asthma report significant stress and negative effects on their QOL as a result of the responsibility of managing the disease.

Quality of Life and Primary Care Management

Unfortunately, in primary care management of childhood asthma, the well-being and QOL of caregivers are often not a chief focus of care. Health visits predominantly focus on symptom management, and the quality of life of the affected child. Further support is available beyond the primary care provider, however broader initiatives such as asthma education programs are limited in accessibility. These programs— offered through health authorities and non-governmental organizations— are generally reserved for children with severe or uncontrolled symptoms, and are primarily found in larger urban centres. Primary care providers are therefore often tasked with providing comprehensive asthma care using what few resources are available to them, such as clinical guidelines. Even within evidence-based practice guidelines for the care of childhood asthma, the acknowledgement of caregiver care/QOL is negligible. For example, in Canada and British Columbia, there are two major guidelines on the management of asthma for

health providers: one set through BC Guidelines (2014), and the other, the aforementioned CTS guidelines (Ducharme et al., 2015; Loughheed et al., 2012). The BC Guidelines publication is only indicated for those 6 years and older with asthma. Though this does not include the focus population for this paper, it still includes the care of a large proportion of children with asthma, and there is no mention of caregiver involvement anywhere in the document. The CTS guidelines, particularly those focused on preschool-aged children (Ducharme et al.) are more comprehensive and specific to the management of childhood asthma. While these guidelines consider the involvement of caregivers in management, the only mention of caregiver quality of life is in regards to referral to specialists, stating that “parental anxiety, need for reassurance, additional education” are indications for referral to an asthma specialist (p. 31). Likewise, when searching US-based guidelines (National Institutes of Health, 2012) I found a similar lack of priority placed on the well-being of caregivers.

Though major guidelines on paediatric asthma management may not adequately address the caregiver experience, there is substantial literature available on this topic. Within the literature I collected on the caregiver experience of having a child with asthma, two consistent themes emerged related to the health provider’s effect on caregiver quality of life: (a) caregiver-provider communication, and (b) caregiver input on management. A study by Carpenter et al. (2013) found that increased caregiver-provider communication (indicated by greater number of questions asked by the provider) was directly associated with increased caregiver quality of life. Likewise, a study by Sleath et al. (2011) addresses the significance of shared decision-making in the management of asthma, and the effects on caregiver satisfaction. Alongside the essential biomedical care needs of children with asthma and their families, these are aspects of care that

primary care providers must consider to promote the overall health of the patient and their family.

Asthma Action Plans

There is an abundance of literature available on best approaches to asthma management in primary care. Overall, asthma action plans (AAPs) are recognized as a gold standard in asthma care. A systematic review of randomized controlled trials by Zemek, Bogal, and Ducharme (2008) supports the use of AAPs to improve outcomes in childhood asthma. Most asthma guidelines worldwide have adopted this approach as best-practice, yet it is estimated that fewer than 25% of patients with asthma have a written AAP (Shah et al., 2011).

AAPs involve a written document provided to the patient or caregiver that usually includes management goals, information on early symptom recognition, step by step instructions for symptomatic treatment, and guidance in determining need for a higher level of care (Tan, Chen, Soo, Ngoh, & Tai, 2013). The most common type of AAP involves a “traffic light” approach, in which each colour (green, yellow, and red) represents a symptom set and the subsequent actions recommended.

Understandably, most literature on AAPs has been focused on decreasing exacerbations of asthma, and not necessarily on the how this translates to QOL in the caregivers of the children with asthma. As AAPs are tools that support communication between providers and caregivers, provide information on the disease, and allow for individualized care of asthma, I suspect that their use could contribute to improved quality of life in caregivers. By completing an integrative literature review, I hope to link together evidence to determine whether this is supported, guided by the following research question: “Can nurse practitioners, as primary care providers, use asthma action plans to improve the quality of life in the caregivers of preschool-aged children

with asthma?” The next step in this process involved a comprehensive literature search to gather studies to review for final analysis. The methodology used in this process will be described in the next chapter.

Chapter Three

Methods

An integrative review of current literature was executed to explore the use of asthma action plans in pediatric populations, and determine how this may affect quality of life (QOL) for caregivers. Torraco (2005) defines an integrative literature review as “a form of research that reviews, critiques, and synthesizes representative literature on a topic in an integrative way such that new frameworks and perspectives on the topic are generated” (p.356). Thus, prior to deciding on a final research topic, I performed an initial search of the literature on pediatric asthma management aimed at uncovering areas in which gaps in evidence remain. Accordingly, the topic I chose to review is guided by the following question: “Can nurse practitioners, as primary care providers, use asthma action plans to improve the quality of life of caregivers of preschool-aged children with asthma?” Through a comprehensive examination of the themes within this research question, I intend to develop recommendations for guiding future practice and research on asthma management.

The literature search process for this integrative literature review occurred in three stages, including (1) developing a search strategy and the preliminary search, (2) a focused search, and (3) a detailed analysis of the final chosen articles.

Search Strategy and Preliminary Search

My preliminary literature search strategy involved a search of four electronic databases through the University of Northern British Columbia library: CINAHL (EBSCOhost), Medline (Ovid), Cochrane Database of Systematic Reviews (CDSR), and PsychINFO (EBSCOhost). I chose these databases because they are specific to health care-related journals. In order to ensure a thorough search of the literature, I began by using a concept map to break down my research

question and extract ideas, which I could develop into search terms. Each term was then searched as a keyword, using appropriate truncation and wildcard functions, with the option to formulate into MeSH terms used, when available (with CINAHL, MEDLINE, and PsychINFO). All MeSH terms were exploded in order to decrease risk of omitting important literature. Table 1 outlines the keyword terms entered, and the resulting subject headings used.

Table 1

Search Terms

Keyword Search (?= Wildcard) (* = Truncation)	MeSH Terms Retrieved			
	CINAHL (EBSCOhost)	MEDLINE (Ovid)	CDSR	PsychINFO (EBSCOhost)
“Quality of life” or “Stress”	<ul style="list-style-type: none"> • Quality of Life • Stress, Psychological 	<ul style="list-style-type: none"> • Quality of Life • Stress, Psychological 	<ul style="list-style-type: none"> • Subject terms not available through this database, keyword terms used 	<ul style="list-style-type: none"> • Quality of Life • Stress
“Parent*”	<ul style="list-style-type: none"> • Parents 	<ul style="list-style-type: none"> • Parents 		<ul style="list-style-type: none"> • Parents
“Asthma”	<ul style="list-style-type: none"> • Asthma 	<ul style="list-style-type: none"> • Asthma 		<ul style="list-style-type: none"> • Asthma
“Chronic disease*”	<ul style="list-style-type: none"> • Chronic Disease 	<ul style="list-style-type: none"> • Chronic Disease 		<ul style="list-style-type: none"> • Chronic Illness
“Child*” Or “P?ediatric*”	<ul style="list-style-type: none"> • No relevant subject terms, keywords used 	<ul style="list-style-type: none"> • Child • Pediatrics 		<ul style="list-style-type: none"> • Pediatrics
“Asthma action plan*”	<ul style="list-style-type: none"> • No relevant subject terms, keywords used 	<ul style="list-style-type: none"> • No relevant subject terms, keywords used 		<ul style="list-style-type: none"> • Not relevant for this database
“Nurse Practitioner*”	<ul style="list-style-type: none"> • Nurse Practitioners • Pediatric Nurse Practitioners 	<ul style="list-style-type: none"> • Nurse Practitioners 		<ul style="list-style-type: none"> • Not relevant for this database
“Primary care”	<ul style="list-style-type: none"> • Primary Health Care 	<ul style="list-style-type: none"> • Primary Health Care 		<ul style="list-style-type: none"> • Not relevant for this database

From these search terms, I formulated Boolean search combinations (see Appendix A) aimed at finding available research on:

- Current use of asthma action plans in paediatric populations
- Management of asthma in primary care, or more specifically by nurse practitioners in primary care
- The experience of having a child with asthma or a chronic illness

Upon completing the preliminary searches, I removed literature that was unsuitable for the purpose of this paper, by applying minor limiters including language (English), and type of publication (peer-reviewed journal article).

Focused Search

Due to the high volume of results (1384 articles) following the preliminary search, my next step involved narrowing the results by screening titles and abstracts for relevance. This was carried out using a specific inclusion and exclusion criteria, depicted in Table 2.

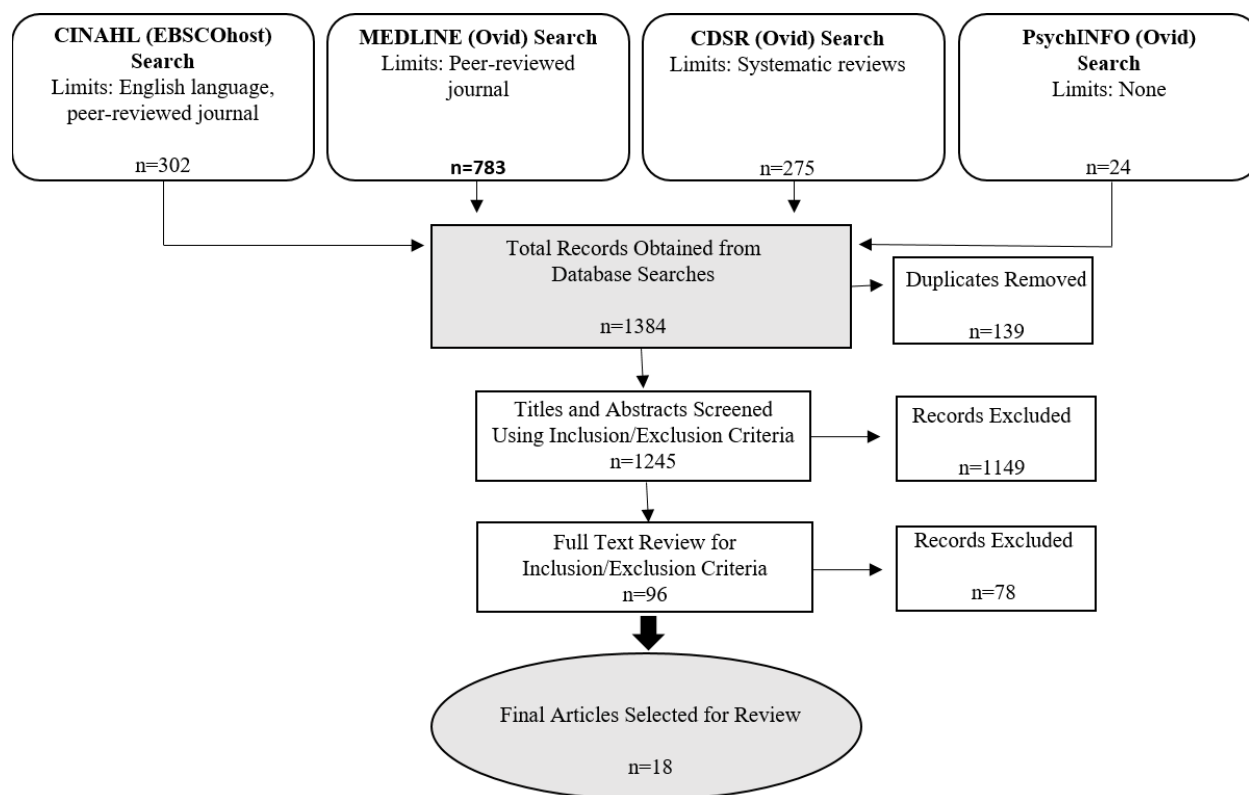
The final part of this stage involved a full review of each article that met the requirements following abstract and title screening to further narrow the results. In the end, I identified 18 studies eligible for inclusion in this integrative literature review. Figure 1 illustrates a summary of the full search process.

Table 2

Inclusion and Exclusion Criteria

Inclusion	Exclusion	Rationale
Published between 2000 and 2015	Published prior to 2000	To reflect recent and current practices. This period also coincides with the major implementation of NPs in Canada.
May be qualitative or quantitative research. May be any level of research (e.g. original studies, systematic reviews, meta-analyses)	Non-peer-reviewed research articles, opinion pieces, editorials, news releases, magazine articles.	Seeking credible sources within the databases.
Abstract available, or title appears relevant if no abstract is available.	No abstract available and title does not appear relevant.	To assist in limiting search results to pertinent articles to review.
Addresses at least one of the following: <ul style="list-style-type: none"> • Asthma in children, with preference given to those addressing preschool aged children • Caregiver experience of having a child with asthma • Primary care/NP approaches to asthma management • Use of asthma action plans in paediatrics 	Specific focus on acute care management or on the pharmacological management of asthma	As I have not found literature that addresses all aspects of my research topic, I am looking for these pieces to bridge the evidence together.
Studies based in any country, provided that the sociodemographic factors of the country would not overtly affect generalizability to Canadian/BC populations.	Studies specifically directed at the demographics/population or health system of a country outside of Canada	To limit to research pertinent to Canadians and British Columbians.

Figure 1.

Search Strategy and Detailed Results**Analysis**

The last stage of the literature review was directed at critically analyzing each of the final 18 articles. This analysis was executed using a literature review matrix. Column headings in the matrix were guided both by literature appraisal guidelines and themes that emerged from the articles reviewed. I used the Critical Appraisal Skills Programme (CASP, 2013) checklist as a guideline to address the rigor, validity, and strength of evidence in each article. Three themes emerged in my initial full review of each article, and I was able to incorporate these into the matrix to better facilitate cross-analysis of articles. These themes included (a) the caregiver context of disease and factors that influence QOL, (b) communication between caregivers and primary care providers, and (c) evidence surrounding particular family-centered management strategies for childhood asthma. Within the matrix, articles were divided into sections based on

these themes, though it should be noted that themes had a degree of crossover within articles.

The results of this analysis are presented in the next chapter.

Chapter Four

Findings

The main purpose of the literature review was to gather and integrate current evidence on caregiver quality of life (QOL), primary care management, and the use of asthma action plans (AAPs) within the context of preschool-aged children with asthma. I guided this analysis by the research question: “Can nurse practitioners, as primary care providers, use asthma action plans to improve the quality of life in the caregivers of preschool-aged children with asthma?” An integrative literature review approach was used, with a final literature sample of 18 articles, which were analyzed using a literature review matrix. The literature analysis revealed three main themes relating to the research question: (a) the caregiver context of disease and factors that influence QOL, (b) communication between caregivers and primary care providers, and (c) evidence surrounding particular management strategies for childhood asthma that promote caregiver QOL. In this chapter, I will focus on expanding on these themes as they are presented within individual articles. Details on the quality, reliability, and utility of each article are summarized in a shortened version of literature review matrix used in the literature analysis, modified for this purpose (see Appendix C).

The Caregiver Context of Disease: Factors Influencing QOL

Understanding the caregiver context of childhood asthma emerged as an important theme within the literature. The evidence to support the idea that caregiver QOL is affected in childhood asthma— and particularly with preschool-aged children— was overwhelming. This theme was important in my literature analysis, as in order to answer the research question about improving QOL, it was necessary to understand *what* was leading to impaired QOL in

caregivers. Within this section, I will therefore discuss two sub-themes that emerged as factors influencing QOL in caregivers: factors related to caregiver burden, and individual factors.

Caregiver burden refers to the caregiving demands that are beyond those a parent or caregiver would typically be responsible for when raising a child. This may include various degrees of routine rearrangement, symptom monitoring, medication administration, medical visits, missed work and school, and avoidance of triggers. Individual factors include sociodemographic influences, coping mechanisms, and self-efficacy in managing the disease. Of the 18 articles chosen for review, nine articles considered disease burden, the caregiver context of disease in asthma and how these can be related to caregiver QOL.

The first article chosen for review was a longitudinal study by Bellin et al (2013). In this study, the researchers examined the stress and QOL in the caregivers of children with poorly-controlled asthma. Disease burden was a primary focus, with the target population—children with poorly controlled asthma—having presumably high caregiver burden. Using the Activity Limitation Scale of the Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) as an indicator of QOL, the researchers found that perception of life stress and perception of higher care demands by the caregiver during periods of poor asthma control correlated with impaired QOL ratings ($b = -0.19$ to -0.26 ; $p = 0.03$). Verification of validity and reliability of the Activity Limitation Scale of the PACQLQ is indicated by a Cronbach α value of 0.83, and an intraclass correlation coefficient of 0.84. A major limitation to this study however, was in the sample population. Most of the caregiver participants recruited were mothers, and were single, unemployed, and low-income. The children were primarily African-American with poorly-controlled asthma, limiting the generalizability of these results.

Studies by Cerdan, Alpert, Moonie, Cyrkiel, and Rue (2012), Silva, Crespo, Carona, and Canavarro (2015), and Walker et al. (2008) also demonstrated an association between caregiver burden and caregiver QOL. Cerdan et al. found that higher asthma severity in children, and the resulting increased burden of this, reflect lower PACQLQ scores and thus, lower QOL in caregivers ($r = -0.34$; $p = 0.001$). Again, the authors of the study indicate the validity and reliability of the PACQLQ by reviewing the correlation data: indicators and QOL scores were well-correlated with QOL, with r scores ranging from 0.22-0.51 and p values for particular indicators ranging from < 0.1 to < 0.0001 . While this study had a fairly small sample size (101 caregivers), it included families of variable sociodemographic groups, allowing for better generalizability than the study by Bellin et al. (2013). Likewise, the studies by Silva et al. and Walker et al. reinforce the evidence that higher caregiver burden is associated with decreased QOL using population samples from a variety of sociodemographic groups.

In considering the target age of this integrative literature review, three articles addressed the connection between higher caregiver burden and having a preschool-aged child with asthma. Clark and Chalmers (2003), and Silva et al. (2015) distinguish the increased dependency young children have on their caregivers for asthma care compared to older children, thus speculating greater caregiver burden. Kieckhefer and Ratcliffe (2000) found that the caregivers of children under the age of five frequently experience a high level of discomfort and uncertainty around recognizing and responding to asthma symptoms. Similarly, Trzcieniecka-Green, Bargiel-Matusiewicz, Wilczynska, and Omar (2015) found that a new diagnosis of asthma, which is often the case in preschoolers with asthma, may be associated with lower caregiver QOL when compared to caregivers of children with an asthma diagnosis of over one year ($\chi^2 = 5.17$, $p < 0.05$). This may indicate that as caregivers adjust to the burden of care, QOL improves.

However, this finding was only demonstrated with statistical significance in caregivers 20-30 years of age, and the sample size of the study was small at only 60 caregivers.

Beyond findings related to disease burden, the literature sample revealed that there are multiple factors that contribute to caregiver QOL related to the individual situations of caregivers. Though the results of the studies above may indicate that QOL is affected regardless of sociodemographic factors, it is apparent that factors—such as age, level of education attained, household income, housing, and marital status—may contribute to the *degree* of effect asthma has on a caregiver's QOL. Data retrieved by both Cerdan et al. (2012), and Osman, Baxter-Jones, and Helms (2001) demonstrated an association between certain high-risk sociodemographic groups (e.g. low-income, young maternal age, poor housing) and lower overall QOL. Caregivers with higher incomes reported higher QOL ($r = 0.35$; $p < .001$) (Cerdan et al.), and QOL scores were significantly lower in mothers with a higher social deprivation score (8% lower; $p = .05$), and in mothers under the age of 30 (10% lower; $p < .02$) (Osman et al.).

Individual coping mechanisms of caregivers may also have effects on QOL. In the study by Silva et al. (2015), researchers found that a diagnosis of asthma in a child generally led caregivers to assume one of two coping mechanisms: denial or acceptance. When comparing QOL based on a caregiver denying or accepting the reality of the situation, acceptance marked a positive correlation with QOL ($\beta = 0.29$; $p = 0.01$), leading to a conclusion that assisting the caregiver to understand and accept the disease may promote better QOL.

Finally, it was repeatedly discovered within the literature that caregiver self-efficacy in managing their child's asthma has a tremendous effect on QOL. Carpenter et al. (2013) used the Parent Asthma Self-Efficacy Scale ($\alpha = 0.87$) to assess caregiver confidence in preventing and managing asthma exacerbations, and followed with an assessment of QOL using the PACQLQ.

Within this study, the authors found that caregivers with higher levels of asthma self-efficacy reported better overall QOL ($r = .45, p = .01$). Likewise, the studies by Clark and Chalmers (2003), and Kieckhefer and Ratcliffe (2000) acknowledge the significance of caregiver self-efficacy in asthma management, as asthma interventions are largely carried out independently by caregivers in the home. All three studies thus stress the importance of targeting caregiver self-efficacy when managing childhood asthma. Additionally, these findings correspond well to the aforementioned idea that caregiver QOL is greater in children with a diagnosis for over one year (versus a new diagnosis), assuming that experience with asthma management leads to greater self-efficacy.

Caregiver-Provider Communication

The second major theme I found within my literature review emphasized caregiver-provider communication. From the literature that explored the caregiver experience of childhood asthma, it was apparent that caregivers often felt like “outsiders” during interactions with providers, and felt as though they should have more input on their child’s asthma care. Likewise, in multiple studies the authors concluded that there is a need for providers to better facilitate communication with caregivers in order to gain an understanding of their experiences and better address problems, including impaired caregiver QOL.

In three of the articles, researchers found that caregivers were not adequately involved in discussions regarding their child’s asthma, whether due to low engagement on the part of the caregiver, lack of inclusion or invitation by the provider, or possibly a combination of both. Sleath et al. (2011) audio recorded and examined the interactions that occurred between caregivers and providers during 333 paediatric asthma visits at five different clinics. They found that discussions were largely dominated by providers, few questions were asked by caregivers,

and providers only asked for caregiver input into the management plan during 10% of the visits recorded. Clark and Chalmers (2003) found that many caregivers of preschool-aged children with a new diagnosis of asthma did not feel well-supported by health providers. These feelings were found to be related to the quality of relationship held between the provider and caregiver, which may fluctuate over time. Particular phases of these relationships included entrusting the provider, becoming disillusioned by interactions, and learning the formal and informal rules or “ways” of the health care system. The particular phase the caregiver was in within the relationship contributed to their sense of participation and inclusion in care. In an article by Kieckhefer and Ratcliffe (2000), the authors discuss the importance of acknowledging the expertise of the caregiver, and encouraging shared-decision making in the care of the child. Through focus groups, this study found that caregivers generally feel they have “important information to share with the provider about living with a child with asthma” (p. 125), but do not always feel comfortable initiating this conversation.

In addition to caregivers feeling like outsiders in the management of their child’s asthma, the findings of this literature review indicates that there is a communication gap in discussing the caregiver experience of having a child with asthma. In the study by Kieckhefer and Ratcliff (2000), caregivers were asked “what is one thing that you would like health providers to know about your experiences of living with a child who has asthma?” (p. 123). The results indicated that 18.8% of caregivers wanted providers to know that they felt scared and fearful, 9.4% wanted providers to know that having a child with asthma is difficult, stressful and affects the caregiver’s behaviour, and 6.3% described wanting the provider to understand to degree of burden due to disease monitoring requirements. These findings suggest that the caregiver experience, including their QOL, is not adequately addressed during asthma visits with

providers. Kieckhefer and Ratcliffe also suggest that discussing these concerns, and acknowledging that they are normal feelings may be reassuring to caregivers.

In terms of directly addressing QOL in caregivers of children with asthma, in the studies by Stelmach et al. (2012), and Osman, Baxter-Jones, and Helms (2001), the authors recognize the importance of discussing and assessing caregiver QOL in paediatric management. In both studies, the authors recommend using the PACQLQ in asthma visits as a tool to better acknowledge caregivers in the care of children with asthma.

Management Strategies to Promote Caregiver Quality of Life.

One purpose of this literature review was to explore the use of AAPs, determine whether their use would address the caregiver context of disease, and more specifically, whether they can promote improved QOL in caregivers. Thus, this final theme focuses on key strategies of asthma management that can contribute to improvement of caregiver QOL, and explores how AAPs can contribute to meeting these standards. Key strategies found within the literature focus on asthma education and asthma self-efficacy by caregivers.

As previously mentioned, asthma self-efficacy and management have emerged as important factors in promoting caregiver QOL in childhood asthma. In further review of the articles focused on management strategies, authors acknowledged that education plays a role in a caregiver's ability to independently manage their child's asthma. Shah, Roydhouse, and Sawyer (2008) discuss this in their study, highlighting that asthma education is needed to teach information and skills to caregivers in order to effectively manage their child's asthma. Georgiou et al. (2003) implemented a large-scale asthma education intervention involving written information, videos, reminder aids, and telephone assistance, and found that these strategies significantly lessened the burden of asthma on caregivers. Similarly, Bentley, Ludlow, Meier,

and Baydala (2005) reinforce the significance of education in the management of childhood asthma. In this study, the authors not only found that detailed educational interventions increase caregiver's confidence in their ability to manage their child's asthma, but also reveal significant improvements in caregiver QOL (6.3-12% increase in QOL scores, $p < 0.05$). However, it should be noted that the educational intervention involved in this study was based out of a specialized asthma clinic, thus limiting generalizability to primary care practices.

It is clear within the literature that caregivers see value in AAPs (MacGillivray & Flavin, 2014; Tan et al., 2013). A primary function of an AAP is to promote independence in asthma management by reminding patients and caregivers of the treatment plan, and provide step-by-step instructions on how to carry out this treatment plan (Bhagal, Zemek, & Ducharme, 2009; Dinakar, Van Osdol, & Wible, 2004). Tan et al. confirm in their study that AAPs increase confidence in caregiver management of asthma and improved understanding of the illness. So, while much of the literature on AAPs is focused on using them as a tool to decrease exacerbations and hospitalizations (Bhagal et al., 2009; Dinakar et al., 2004), it is possible that their role may indirectly contribute to caregiver QOL, based on the information gathered in this literature review. Additionally, within the articles on AAPs, it was found that these tools contribute to improved caregiver-provider communication and better individualization of care; factors also found within this review to contribute to caregiver QOL.

Though AAPs may provide some education and information on asthma, an important sub-theme that emerged within the literature specific to AAPs emphasized that they are only a tool, and as such should only be used as a *part* of a larger educational intervention. Of the four studies on AAPs from the literature sample, three reported the use of AAPs in conjunction with educational interventions (Bhagal et al., 2009; Dinakar et al., 2004; Tan et al., 2013). These

recommendations, however, are postulated by the authors without sufficient evidence. This is further addressed by Bhogal et al. (2009) in their systematic review of randomized controlled trials, in which the authors acknowledge the lack of research addressing whether AAPs are truthfully more effective with the addition of educational interventions, and implying that stand-alone use may offer equal benefit.

To summarize, this analysis has provided a critical review of common themes within the literature gathered on current primary care management of childhood asthma, caregiver QOL, and AAP use. In consideration of the research question, “Can nurse practitioners, as primary care providers, use asthma action plans to improve the quality of life in the caregivers of preschool-aged children with asthma?”, this analysis considers the factors influencing caregiver QOL, the dynamics involved in caregiver-provider communication, and particular strategies that can promote improved caregiver QOL. The next chapter of this paper provides a discussion of these findings. It includes recommendations for clinical practice, implications for NP practice, and limitations and recommendations for future research.

Chapter Five

Discussion

Through this literature review, I was able to explore the topic of caregiver quality of life (QOL) in childhood asthma. Guided by the question, “Can nurse practitioners, as primary care providers, use asthma action plans to improve the quality of life in the caregivers of preschool-aged children with asthma?”, I have examined a combination of qualitative and quantitative studies concerning the caregiver experience of childhood asthma, the primary care management of childhood asthma, and the use of an asthma action plan (AAP), in this management. This chapter is aimed at discussing how the assembled literature supports the hypothesis that the use of the asthma action plans in primary care can contribute to improved QOL in caregivers of preschoolers with asthma. I will begin by reviewing the key findings and discussing the proposed recommendations for clinical practice. I will follow with a consideration of the implications for practice, including specific inferences for NPs. Finally, I will conclude this chapter with a discussion of the limitations of this project, and provide recommendations for future research on the topic of preschool-aged asthma and caregiver QOL.

Recommendations for Clinical Practice

Three key findings were identified as paramount in answering the research question. First, it was found that the factors influencing caregiver QOL are multifaceted, involving a combination of external and personal factors related to the caregivers. Second, it was found that caregiver-provider communication practices are a barrier in both assessing caregiver QOL, and in promoting practices that encourage improved QOL in caregivers. Lastly, it was found that AAPs, along with other concurrent strategies, have the potential to support providers in improving low

caregiver QOL in childhood asthma. Each of these findings provided direction for making recommendations for clinical practice.

Addressing factors influencing QOL

Through the literature analysis, it was found that low QOL in the caregivers of children with asthma is associated with both external factors related to the caregiver burden in childhood asthma, and the individual factors of the caregivers. The key external factors associated with low caregiver QOL corresponded to those elements causing increased caregiver burden, which subsequently led to decreased QOL. These included:

- Having a child with a more severe form of asthma, and the increased demands this has on the caregiver (Cerdan et al., 2012).
- Having a child with poorly-controlled asthma, and managing acute asthma exacerbations (Bellin et al., 2013; Silva et al., 2015; Walker et al., 2008).
- Having a young child with asthma, specifically preschool-aged, and the associated higher dependency on the caregiver (Clark & Chalmers, 2003; Silva et al., 2015).
- Having a child with a new diagnosis of asthma, and the associated discomfort and uncertainty in recognizing and responding to symptoms (Trzcieniecka-Green et al., 2015).

Key individual factors associated with decreased QOL in caregivers corresponded to sociodemographic factors, and the personal coping skills of the caregivers. These included:

- Belonging to a sociodemographic group considered “high-risk” for health disparities. The examples provided in the literature included young maternal age, low-income, and certain places of residence (Cerdan et al., 2012; Osman et al., 2001).

- Coping mechanisms; specifically, denial versus acceptance of the responsibilities associated with managing their child's asthma (Silva et al., 2015).
- Confidence and self-efficacy in managing their child's asthma (Carpenter et al., 2013; Clark & Chalmers, 2003; Kieckhefer & Ratcliffe, 2000).

These factors suggest that actions aimed at improving asthma control, decreasing the demand of care, increasing caregiver knowledge, improving confidence and self-efficacy in asthma management, improving caregiver coping mechanisms, and addressing sociodemographic risk factors could potentially improve caregiver QOL. Implementing AAPs into primary care asthma management is a small step that may address several of these objectives. Typically, AAPs include management goals, information for early symptom recognition, instructions for treatment of specific symptoms, and guidance to assist caregivers in deciding whether a higher level of care is needed (Tan et al., 2013). These characteristics are intended to provide the caregiver or child with the information needed to independently manage symptoms, thus supporting self-efficacy and prevention of exacerbations, thus improving control and decreasing demands of care. Many AAPs also contain simple, straightforward information on individual asthma triggers and instructions for correct use of device (Province of British Columbia, n.d.), addressing the need for information to increase caregiver knowledge. Furthermore, I would simply expect that having a detailed, written AAP would contribute to comfort and confidence in care, based on an assumption that AAPs provide reinforcement when a caregiver is feeling uncertain on how to proceed with asthma management. However, the literature reviewed further supports this theory, revealing explicit evidence that caregivers find comfort in having an AAP, and have an increased sense of confidence as a result of their use (Tan et al.) Finally, while they are unquestionably important contributors to caregiver QOL, the complex nature of addressing sociodemographic

risk factors and individual coping mechanisms to improve QOL places these indicators beyond the scope of this paper.

Addressing caregiver-provider communication concerns

The main issues that emerged in this review related to caregiver-provider communication involved poor inclusion of caregiver input in management planning, and inadequate acknowledgement and support of the caregiver experience of childhood asthma. Recommendations for practice related to these findings are therefore directed at the provider's role in facilitating caregiver-provider communication, involving the caregiver in developing the management plan, and inquiring about QOL at health visits.

As reported by Sleath et al., (2011) it is not uncommon for providers to dominate the discussion during asthma visits. Supporting reciprocal communication during these interactions has the potential to provide a better understanding of the family's individual situation, promote a stronger caregiver-provider relationship, allow for more individualized and effective care, and consequently contribute to improved QOL (Clark & Chalmers, 2003; Kieckhefer & Ratcliffe, 2000). Facilitating better communication may be as simple as directing more questions to caregivers during visits, encouraging them to ask questions, and allowing mutual dialogue to occur. Likewise, the provider can use the AAP as a tool to promote discussion by assuming a collaborative approach with the caregiver in developing the home management plan. For example, by developing the AAP together, the provider may learn that the caregiver is struggling to remember to administer morning doses of the child's twice-daily inhaled corticosteroid (ICS). If appropriate, they could instead consider an ICS with available once-daily dosing. Hence, AAPs are not only a tool that can directly effect caregiver quality of life, but has the potential to be used as an indirect method by supporting communication.

Part of the provider's role in facilitating better caregiver-provider communication should also involve assessing caregiver QOL (Osman et al., 2001; Stelmach et al., 2012). Within the literature on caregiver QOL, the PACQLQ stood out as a well-supported tool for measuring and addressing the effects of childhood asthma on caregiver QOL. The tool is short, simple, and provides an objective measure of caregiver QOL that can then be reassessed with subsequent visits. This tool, along with other QOL assessment tools, can therefore be used to promote communication and understanding between caregivers and providers.

Larger-scale interventions aimed at supporting providers may also be beneficial in promoting improved caregiver-provider communication. As previously noted in this paper, current guidelines for the management of childhood asthma offer little recognition of the important role caregivers and families play. I would thus recommend that asthma guidelines directed at paediatric populations include greater acknowledgement of this unique dynamic, with guidance for practitioners, such as the use of tools like the PACQLQ.

Use of AAPs to promote improved caregiver QOL

While AAPs are by no means a novel concept in asthma care, it was found within the literature that a large proportion of patients with asthma do not have AAPs (Shah et al., 2011). In addition to the prevailing, well-documented reasons for their use, AAPs have been clearly verified within this literature review as a tool providers may use to promote and contribute to better QOL in caregivers. AAPs are therefore recommended to be implemented in the care of all children with asthma.

It is not apparent in the literature *why* AAPs are often not included in a child's management plan, however I would suspect that this is either due to oversight, or related to time and resource constraints in the primary care setting. I believe that increasing the use of AAPs is highly

dependent on uptake by primary providers, and thus it is necessary to consider AAP practices that center on ease of use and efficiency. Integrating routine use into practice can be challenging, however this can be supported using available resources and technology. AAP templates are easily obtained online, and are most often free of charge. Providers can choose hard-copy templates, or electronic templates that can be completed online and either printed or emailed to the family, depending on which they would consider more convenient. Having preprinted AAP templates available may promote greater use. Likewise, some providers may prefer to have a direct link on their desktop to an electronic template that can be completed and saved directly into the patient's electronic medical record (EMR), or printed and filed. With the growth of EMRs, there are even programs like iAAP (Minnesota Department of Health, 2009), which draw information from a patient's EMR to provide individual AAP recommendations and allows for easy development of the AAP, which is then automatically filed into the patient's EMR.

When considering AAP use in practice, it is also important to recognize that not all AAPs are created equal. While most AAPs are developed consistently, take an evidence-based approach to guiding home-based management, and are clear and simple to use, there remains considerable variation among those available.

The main variations seen amongst AAPs includes whether they are symptom or peak-flow based plans, differences in treatment recommendations for each zone of asthma severity (i.e. green, yellow, and red zones), and availability of additional reference information. Both MacGillivray and Flavin (2014), and Zemek et al. (2008) found in their studies that symptom-based plans are superior to peak-flow based plans for addressing exacerbations. Additionally, the proper use of peak-flow meters is not realistic in preschool populations and therefore these should not be used in this population. MacGillivray and Falvin also provide further

recommendations for AAPs used in Canada, based on alignment with current CTS guidelines. The authors recommend that the descriptors defining each zone be clear and concise, provide space for child-specific interventions, but also provide practitioners with treatment guidance for each zone per the current CTS guidelines. For example, the authors found that many AAPs provide a space for providers to write a step-up dose for inhaled corticosteroids (ICS) during acute exacerbations, whereas current guidelines do not recommend increasing an ICS during acute exacerbations due to a lack of data supporting this intervention. The other main recommendation by the authors stressed the importance of including information on the child's individual asthma triggers in the plan. The AAP developed by the Province of British Columbia (n.d.) is designed specifically for preschoolers and is an example of an AAP that meets all of the the aforementioned recommendations (see Appendix D).

Beyond the use of AAPs, one of the most significant findings that emerged from this review was the importance of providing caregivers with detailed education on asthma and asthma management. In studies by Bentley et al. (2005) and Tan et al. (2013), comprehensive educational interventions were directly associated with increased caregiver confidence and self-efficacy in managing their child's asthma, and improved overall QOL. While this review has established that AAPs are a tool that can promote improved QOL in the caregivers of preschool-aged children with asthma, it has also revealed that they are only one of many practices that should be considered (Bhogan et al., 2009; Dinakar et al., 2004; Tan et al.). Thus, this recommendation stresses the significance of using AAPs *alongside* educational interventions for caregivers. I can appreciate that in the primary care setting this can be a challenge, as appointment times are limited. If resources are available to support asthma teaching, providers are then encouraged to make use of these options (e.g. access to asthma educators, group

learning sessions, online resources). Otherwise, it may be necessary to schedule follow-up appointments to complete the adequate education with children and their caregivers. Overall, however, an AAP is an excellent place to start, and should be provided regardless of whether formal asthma education is available.

Interventions that go beyond the scope of individual providers, such as those implemented at the community, health authority, or provincial level can also be beneficial in supporting the educational component of asthma management, and contribute towards efforts for improved caregiver QOL. Currently, programs are available through health authorities aimed at asthma care and education for children and their families. BC Children's Hospital (2016) provides asthma consultation and education, however this service is aimed at children with poorly-controlled or difficult to manage asthma, and no longer accepts referrals for education alone. Throughout the province, educational services are available (Canadian Lung Association, 2015), though are generally limited to larger urban centers, limiting access for many families. As this review has established that caregiver QOL is affected in most cases of childhood asthma, making formal educational interventions standard for *all* families experiencing childhood asthma may be valuable for improving QOL. Furthermore, with the success and growth of programs using new technologies like the videoconferencing used with the Provincial Health Services Authority Telehealth Services (2016), such services may be deliverable through more cost-efficient and convenient means.

Working towards improved QOL for caregivers of preschool-aged children with asthma is best approached using multiple interventions and methods aimed at addressing the causes of decreased QOL, current issues around caregiver-provider communication, and using evidence-

based approach to management. Table 3 summarizes the key recommendations for clinical practice.

Table 3

Key Recommendations for Clinical Practice

Target Audience	Recommendations	Suggestions for Implementation
<p>Individual providers:</p> <ul style="list-style-type: none"> • NPs in primary care • General practitioners • Other primary care providers 	<ol style="list-style-type: none"> 1. Ensure all children, especially preschoolers, with a diagnosis of asthma or with symptoms suggestive of asthma are provided with an individualized AAP 2. Work towards better conscious facilitation of reciprocal communication with caregivers. 3. Promote the use of AAPs concurrently with comprehensive asthma education when available. 4. Assess QOL in caregivers throughout the course of the disease. 	<ul style="list-style-type: none"> • Have easy access to AAPs for primary care visits: <ul style="list-style-type: none"> ➢ Hard copies available ➢ Link to electronic version on computer desktops ➢ Program/template through EMR (e.g. iAAP) • Ask caregivers questions during visits, and encourage question-asking on their part. • Develop AAPs collaboratively with parents (and children when appropriate). • If asthma education during a primary care visits is not adequate, consider: <ul style="list-style-type: none"> ➢ Scheduling additional visits as needed to complete education ➢ Referring to formal education programs if available ➢ Referring to online asthma resources, such as the Asthma Society of Canada (2016) website, or the extensive list of tools and resources available to caregivers on the Asthma and Allergy Foundation of America (2016) website • Use tools to regularly assess caregiver QOL: <ul style="list-style-type: none"> ➢ PACQLQ ➢ WHO Quality of Life assessment instrument (WHOQOL): not limited to caregivers, or to the context of asthma, but addresses cultural and value systems, and individual considerations of QOL. ➢ As with AAPs, tools like the PACQLQ can be integrated into EMRs to promote ease of use.

Target Audience	Recommendations	Suggestions for Implementation
<p>Other key stakeholders:</p> <ul style="list-style-type: none"> • Community programs • Asthma organizations • Health authorities • Asthma guideline developers 	<ol style="list-style-type: none"> 1. Increase access to asthma education programs. 2. Make formal asthma education standard for all preschool-aged children with asthma, or with symptoms suggestive of asthma. 3. Provide better inclusion of issues affecting the caregivers of children with asthma—such as QOL—into current management guidelines. 	<ul style="list-style-type: none"> • Consider funding and implementation of cost-effective asthma education delivery. <ul style="list-style-type: none"> ➤ Online education modules ➤ Telehealth services • Provider support: For example, NPs, GPs, asthma educators, and other asthma care providers can advocate for such services through project proposals to potential funders, presenting at conferences, or even simply by discussing the at health authority meetings or with other health professionals.

Implications for Nurse Practitioner Practice

The findings from this literature review lead to many potential implications for NP practice. In Canada—and in British Columbia in particular— NPs are emerging as important members of the health care team. Many of the positions developed for NPs are in primary care; in 2013 56% of NPs in BC were employed in community or primary health care settings (Sangster-Gormley et al., 2014). While many children with asthma may receive specialty consultation for asthma—for example through emergency departments, by respirologists, or in specialty asthma clinics—the majority of health visits for asthma management occur in the primary care setting (American College of Allergy, Asthma & Immunology, 2015). Additionally, in BC, asthma is classified as a disease that can be independently diagnosed and managed by entry-level paediatric and family NPs (College of Registered Nurses of British Columbia, 2015). Therefore, many NPs may be responsible for the diagnosis and ongoing management of asthma in children, and thus have the potential to play a key role in addressing the altered QOL of caregivers.

Though in this project I focused on NP and primary care management of childhood asthma, it is not to say implications cannot extend to other health providers and other sectors of care. As health care continues to adopt more collaborative approaches to disease management, children with asthma and their families may see a variety of providers for their asthma needs. For example, within a primary care centre, a child may be connected to a NP or physician primary care provider, a social worker, a pharmacist, a respiratory therapist, and/or a physiotherapist. Having common goals around interventions—like the use of AAPs—can provide consistency in care and better address the needs of these families. Thus, any health provider working with families affected by childhood asthma can use or promote the principles and recommendations discussed in this review in order to support improved QOL in the caregivers.

Limitations and Recommendations for Future Research

The main limitations of this review were related to the narrow size and scope. Addressing sociodemographic risk factors was mentioned in discussing the contributors to decreased caregiver QOL, however the complexity of these factors extend beyond the scope of this paper. Likewise, addressing the individual coping mechanisms of caregivers is another factor requiring greater exploration than what was provided by the literature search and analysis of this review. Thus, my first recommendation is for further depth of research regarding caregiver QOL in relation to the sociodemographic risk factors and the individual coping mechanisms of caregivers in order to better identify and support these groups.

While education was revealed as an important aspect for promoting caregiver QOL, this review lacks detail on specific components of education that may be key in addressing this, and whether formal education is an essential concomitant intervention with AAPs. Furthermore, though the evidence in this paper upholds the hypothesis that AAPs improve QOL in caregivers, the idea that they are an unrivaled solution is limiting, in that there are certainly other possible interventions that may support QOL in caregivers. Consequently, I think it is not only important to further explore specific educational interventions aimed at improving QOL in caregivers, but to consider interventions beyond AAPs and educational interventions. While no specific examples pertaining to this emerged in the literature review, this may include such interventions as caregiver support groups, family or individual counselling services, or services to provide asthma teaching to family members or other caregivers (e.g. daycare staff) so they may better support the primary caregivers. This paper also considers the possible indirect effects of AAPs, such as their use as a tool to improve communication between caregivers and providers. I believe

that this topic would benefit from further research on specific ways in which AAPs should be utilized to promote caregiver QOL, including their role in supporting communication.

Finally, this review has focused solely on childhood asthma and the effects of this particular chronic disease on caregivers. While depth has been provided to this very specific topic within this review, I believe that it provides implications for other paediatric chronic illnesses (e.g. type 1 diabetes mellitus, epilepsy, severe allergies) and the similar challenges that may arise in these illnesses for caregivers. I would therefore encourage further research on addressing QOL in caregivers to encompass a greater range of health challenges affecting paediatric populations and their families.

Chapter Six

Conclusion

As one of the most prevalent childhood chronic illnesses both worldwide and in Canada, the overall effects of asthma are extensive. While efforts are often concentrated on addressing the biomedical and economic issues associated with the disease, it is well known that asthma has considerable effects on individual family units of children with asthma, particularly on caregivers. Quality of life (QOL) of caregivers has emerged as an important concern within the context of childhood asthma, with even greater emphasis when this concerns young children, like preschoolers. The preceding chapters of this paper identified that current primary care management strategies are not sufficient in addressing the caregiver experience of asthma in this population.

Asthma action plans (AAPs) have been established as a key tool in asthma management for improving asthma outcomes, and preventing exacerbations and hospitalizations, however there is little documentation on the effects of AAPs on caregiver QOL. Thus, this integrative literature review was aimed at answering the following research question: “Can nurse practitioners, as primary care providers, use asthma action plans to improve the quality of life in the caregivers of preschool-aged children with asthma?”

A comprehensive review of the literature was undertaken to explore this question. Eighteen studies were selected for the final literature sample, allowing for an in-depth analysis of the caregiver experience of childhood and preschool-aged asthma, current trends in primary care management of childhood asthma, and the use of AAPs in childhood asthma. The analysis revealed three main themes related to this topic in the literature. These included: 1) the specific factors that contribute to decreased caregiver QOL, 2) issues regarding caregiver-provider

communication, and 3) evidence supporting particular asthma management strategies for promoting improved caregiver QOL, including AAPs.

Overall, the results of this review not only support the hypothesis that nurse practitioners in primary care can use AAPs to improve QOL in the caregivers of preschool-aged children with asthma, but extend to recommend further applications, such as the use of educational interventions, and the possibility of crossover to include other health providers beyond NPs. Furthermore, this review provides insight for prospective research to build on the findings and recommendations for QOL in caregivers of children with asthma, as well as the potential for implications for other childhood chronic illnesses.

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Appendix A

Boolean Search Combinations

- CINAHL (EBSCOhost): October 3, 2015
- MEDLINE (Ovid): October 3, 2015
- Cochrane Database of Systematic Reviews: October 4, 2015

1. Quality of Life/Stress	9. 3 OR 4
2. Parents	10. 6 OR 7
3. Asthma	11. 5 OR 9
4. Chronic Disease	12. 5 AND 3
5. Child/Paediatric	13. 1 AND 2 AND 11
6. Asthma Action Plans	14. 5 AND 6
7. Nurse Practitioner	15. 10 AND 12
8. Primary Care	
- PsychINFO (EBSCOhost): October 15, 2015

1. Quality of Life/Stress
2. Parents
3. Asthma
4. Chronic Illness
5. Pediatrics
6. 3 OR 4
7. 5 AND 6
8. 1 AND 2 AND 7

Appendix B

PACQLQ ¹

PAEDIATRIC ASTHMA CAREGIVER'S QUALITY OF LIFE QUESTIONNAIRE (PACQLQ)

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Development and validation supported by
FISONS CORPORATION



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JANUARY 2001

Revised 08 December 2010
PACQLQ - North American English Version
PACQLQ_AU1.0_eng-CAref.doc

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PAEDIATRIC ASTHMA CAREGIVER'S QUALITY OF LIFE QUESTIONNAIRE

PATIENT ID: _____ VISIT #: _____

PT'S INITIALS: _____ DATE: _____

Page 1 of 2

This questionnaire is designed to find out how you have been during the last week. We want to know about the ways in which your child's asthma has interfered with your normal daily activities and how this has made you feel. Please answer each question by placing a check mark [X] in the appropriate box. You may only check one box per question.

DURING THE PAST WEEK, **HOW OFTEN:**

	All of the Time	Most of the Time	Quite Often	Some of the Time	Once in a While	Hardly Any of the Time	None of the Time
	1	2	3	4	5	6	7
1. Did you feel helpless or frightened when your child experienced cough, wheeze, or breathlessness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Did your family need to change plans because of your child's asthma?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Did you feel frustrated or impatient because your child was irritable due to asthma?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Did your child's asthma interfere with your job or work around the house?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Did you feel upset because of your child's cough, wheeze or breathlessness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Did you have sleepless nights because of your child's asthma?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were you bothered because your child's asthma interfered with family relationships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Were you awakened during the night because of your child's asthma?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Did you feel angry that your child has asthma?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1

Revised 08 December 2010
PACQLQ - North American English Version
PACQLQ_AU1.0_eng-CAori.doc

PAEDIATRIC ASTHMA CAREGIVER'S QUALITY OF LIFE QUESTIONNAIRE

PATIENT ID: _____ VISIT #: _____

PT'S INITIALS: _____ DATE: _____

Page 2 of 2

DURING THE PAST WEEK, HOW WORRIED OR CONCERNED WERE YOU:

	Very, Very Worried/ Concerned	Very Worried/ Concerned	Fairly Worried/ Concerned	Somewhat Worried/ Concerned	A little Worried/ Concerned	Hardly Worried/ Concerned	Not Worried/ Concerned
	1	2	3	4	5	6	7
10. About your child's performance of normal daily activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. About your child's asthma medications and side effects?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. About being over-protective of your child?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. About your child being able to lead a normal life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

DOMAIN CODE:

Activity Limitation: 2, 4, 6, 8

Emotional Function: 1, 3, 5, 7, 9, 10, 11, 12, 13

Appendix C

Literature Review Matrix

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Bellin et al., 2013)</p> <p>Longitudinal quantitative study examining changes in QOL over 12 months related to a behavioral/educational intervention. Part of a larger randomized controlled trial (RCT)</p> <p>Intervention: Two home visits by asthma nurse, and assistance arranging follow up appointment.</p>	<p>Had a control group receiving standard asthma education versus intervention group.</p> <p>Objective measures: Comparing PACQLQ scores at baseline, 6 months, and 12 months.</p> <p>Size: caregivers of 300 children with asthma.</p> <p>Sound statistical analysis.</p>	<p>Generalizability: most caregiver participants were female, single, unemployed, and/or low-income. All children had poorly-controlled asthma.</p> <p>US-based; different health system and potentially different caregiver stressors.</p>	<p>Improved PACQLQ scores with intervention group: Baseline 17.98; 6 months 22.75; 12 months 22.87. Both increases statistically significant ($p < .001$)</p> <p>Greater life stress associated with lower QOL at all 3 data collection points: At baseline $b = -.26$ $p = .03$; at 6 months $b = -.19$, $p = .03$; and at 12 months $b = -.21$, $p = .03$.</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Bentley et al., 2005)</p> <p>Longitudinal study aimed at evaluating effects of an asthma program involving education and AAPs on asthma severity and QOL</p>	<p>Canadian study</p> <p>Large sample: Caregivers of 398 children with asthma.</p> <p>Variety of demographics providing good generalizability.</p> <p>Sound statistical analysis.</p>	<p>Sample recruited from one asthma specialty clinic. Did not describe severity of asthma.</p> <p>Often lacked clarity about who the participant was (patient or caregiver).</p> <p>Intervention based on a specialized clinic and interventions by a pediatrician and asthma educators.</p>	<p>Links components of AAPs and QOL, and education alongside AAPs.</p> <p>Statistically significant improvement in caregiver QOL (6.3-12.5% improvement; $p < .05$) and confidence in self-management (41.2% increase in parents “quite confident” post intervention [$p < .05$]), as well as less contact with their family physician (73.6-90% less, $p < .01$), and decreased loss of caregiver productivity (89.1% decrease in days of productivity lost; $p < .01$).</p>
<p>(Bhagal et al., 2009)</p> <p>Systematic review of RCTs to examine the impact of providing AAPs in childhood asthma.</p>	<p>Strength in being a systematic review.</p> <p>Size: Total of 355 patients were represented between the 4 studies reviewed.</p> <p>Samples provided variation in child’s age, gender, and asthma severity. Recruited from a variety of settings. Good generalizability.</p>	<p>Small sample: only 4 RCTs were accepted for the final sample, none of which provided a control group in which no AAP was used. Comparison was between symptom-based AAPs and peak-flow AAPs.</p>	<p>Focused on decreasing exacerbations. Found relative risk 27% lower for children with AAPs based on symptoms. Parents did not prefer one type of AAP over the other.</p> <p>Acknowledges the importance of using AAPs only as a part of the intervention; education is paramount. Good overview of the purpose of AAPs.</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Carpenter et al., 2013)</p> <p>Secondary analysis of data gathered in a previous longitudinal study (Sleath et al., 2011). Examines whether there is any association between patient-provider communication and QOL of children with asthma and their caregivers.</p>	<p>Diverse, large sample consisting of 296 families.</p> <p>Provides consistent, appropriate methods of data collection based on participants (interviews with children and caregivers, followed by surveys of caregivers).</p> <p>Thorough statistical analysis of outcomes as well as variables.</p>	<p>Caregiver QOL not measured using PACQLQ (uses GEE model).</p> <p>Some of the study focus was on communication between the child (aged 8-16) and provider, not necessarily the caregiver which may not be transferable to preschool populations.</p> <p>Patients, caregivers, and providers were all aware they were being audio-recorded, possibly influencing interactions.</p> <p>No control for baseline QOL. Data was only collected at baseline and 1 month later; short duration.</p> <p>Participant were referred to the study based on interest; certain populations/demographics may be more likely to volunteer or show interest.</p>	<p>Correlation between caregiver asthma self-efficacy and QOL ($r = .45, p = .01$).</p> <p>Specifies AAPs as a tool for improving self-efficacy</p> <p>Stresses importance of asthma education and engaging families in discussions during visits in order to promote self-efficacy/effective management.</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Cerdan et al., 2012)</p> <p>Cross-sectional study examining asthma severity and caregiver QOL using 3 surveys (PACQLQ, asthma severity questionnaire, and the sociodemographic factors questionnaire).</p>	<p>Though all participants were recruited from a single clinic, there good variation in demographic information providing generalizability.</p> <p>Reasonable sample size: 101 caregivers of children with asthma.</p>	<p>US-based; different health system potentially providing different variables that in Canada.</p> <p>Cross-sectional design provided data on QOL only for that particular time. Many variables may contribute to QOL at a particular snapshot of time. Longitudinal study may have been a more appropriate design.</p> <p>Selection bias: certain populations may volunteer and respond to surveys.</p>	<p>Provides quality data on caregiver QOL based on the PACQLQ.</p> <p>Found that higher asthma severity correlates with significantly lower PACQLQ scores and thus lower caregiver QOL (Spearman rank correlation = $-.34$; $p = .001$).</p> <p>Considers how sociodemographic influences may impact caregiver QOL (e.g. parents with higher income experienced better QOL (Spearman rank correlation = $.35$; $p < .001$)).</p> <p>Affirms the importance of education in supporting caregiver QOL.</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Clark & Chalmers, 2003)</p> <p>Exploratory descriptive study aimed at examining how providers can help caregivers of children with asthma cope with the disease.</p>	<p>Provides descriptive qualitative data, appropriate for evaluating the caregiver experience of childhood asthma.</p> <p>A Canadian study</p>	<p>Small sample size: 17 parents of 15 children with asthma along with many variables (which parent participated, age of diagnosis, asthma severity) possibly decreases reproducibility.</p> <p>Document retrieved did not include tables, images, or graphs; possibly omitting missing valuable information.</p> <p>Focus is on nursing (RN) role, though may still be applicable to primary care providers.</p>	<p>Focus is on preschool-aged children with asthma.</p> <p>Provided qualitative data on the caregiver experience of having a preschool-aged child with asthma. Found that caregivers experience stress and disruption as a result of the diagnosis.</p> <p>Describes “stages” caregivers experience in coping with the diagnosis and management, and how providers can assist them based on each stage.</p> <p>Stresses the role of the caregiver in this age group and importance of self-efficacy as most asthma care is carried out in the home.</p> <p>Recommends individualized care and management.</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Dinakar et al., 2004)</p> <p>Cross-sectional survey of parents of children with asthma covering possession/usefulness of AAP, asthma severity, and frequency of exacerbations.</p>	<p>Reasonable study size: Caregivers of 75 children with asthma.</p> <p>Good survey return: 95%</p> <p>Variety of asthma severity contributes to generalizability.</p>	<p>US-based; different health system and potentially different caregiver stressors.</p> <p>Convenience sampling: all were recruited from one paediatric clinic. Selection bias may limit generalizability.</p>	<p>Describes trends in AAP use.</p> <p>75% had AAPs in this study.</p> <p>9/10 parents found AAPs to be of value in managing symptoms.</p> <p>Discussion section considers the role education has in supporting AAPs.</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Georgiou et al., 2003)</p> <p>Longitudinal study taken place over 12 months examining the effects of an asthma management program on children and their caregivers, including child's QOL, caregiver's asthma management skills and knowledge, and lost days of work/school.</p>	<p>Large, random sample: 401 families randomly selected from 14 districts involved in a large-scale population-based intervention program.</p> <p>Good variation in demographics providing generalizability.</p>	<p>Mail-in surveys; certain populations may be more likely to respond. Response rate was 28% for the baseline survey, then 40% of the 28% completed the follow-up survey.</p> <p>US-based; different health system potentially providing different variables that in Canada (e.g. cost of health care).</p>	<p>Though interventions were mostly via telephone or multimedia, the study, provides data supporting education for improved outcomes and decreased caregiver burden.</p> <p>Found statistically significant improvement in the caregivers' understanding of asthma management and ability to control asthma triggers (16.7% increase in proper symptom management), improved confidence in managing their child's asthma (8.6% increase in parents feeling "very confident" in self-management abilities), and fewer missed days of work (mean of 2 less annual work days missed) (all <i>p</i> values < .01).</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Kieckhefer & Ratcliffe, 2000)</p> <p>Qualitative study; data obtained through focus groups. Aimed at exploring the fears of caregivers, and what caregivers want provider to know about having a child with asthma.</p>	<p>Provides descriptive qualitative data, appropriate for evaluating the caregiver experience of childhood asthma.</p> <p>Reasonable sample size for a qualitative study: 52 caregivers of children with asthma.</p>	<p>Large variation in age: sample involved caregivers of children ages 18 months to 19 years. The caregiver experiences is likely very different in a 19 year-old child than in a preschool aged-child.</p> <p>Convenience sampling: caregivers were recruited from an asthma education conference earlier that day (possible selection bias).</p> <p>Poor generalizability; participants were mainly middle-class, urban families.</p> <p>Focus groups: certain members can influence the conversation and how others participate discussion.</p>	<p>Applies findings to the use of AAPs: encourages providers to discuss fears and concerns with caregivers, and integrate individual concerns into AAPs.</p> <p>Acknowledges the “parent as the expert” and the importance of involving them in developing the management plan.</p> <p>Found that caregivers want repeated education, not just at diagnosis or with exacerbation.</p> <p>Discusses the importance of education and communication to promote caregiver self-efficacy in managing their child’s asthma.</p> <p>Acknowledges the unique challenges parents of young children (under 11 years-old) experience.</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(MacGillivray & Flavin, 2014)</p> <p>Review and comparison of the different formats of AAPs used in Canada.</p>	<p>Canadian-focused</p> <p>Large sample: 17 different types of AAPs were reviewed.</p>	<p>Assumes that variation in AAPs causes confusion to users.</p>	<p>Literature review identifies that patients find most value in clear, specific AAPs for managing symptoms.</p> <p>Provides recommendations for types of AAPs and highlights that parents find AAPs useful.</p>
<p>(Osman et al., 2001)</p> <p>Longitudinal study aimed at validating the use of the PACQLQ with the caregivers of preschool-aged children with asthma.</p>	<p>Thorough statistical analysis.</p> <p>Mixed demographics from urban and rural primary care practices.</p> <p>Though study was completed in Scotland and there may be unique variable as a result of this, the health systems are comparable.</p>	<p>Small sample size: 62 caregivers</p> <p>Most children were found to have relatively mild asthma, limiting generalizability.</p>	<p>Focus on caregiver QOL in preschool-aged children with asthma.</p> <p>Uses PACQLQ as measurement tool. PACQLQ not previously validated for children <7 years; this study validates sensitivity of the PACQLQ in preschool-aged children.</p> <p>Also provided data supporting the associations between caregiver QOL and sociodemographic factors (maternal age <30 = 10% lower QOL score [$p = .02$]; higher social deprivation score = 8% lower QOL score), and asthma symptoms and QOL (as symptoms reduced, QOL scores improved; $r = .69$, $p = .05$).</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Shah et al., 2008)</p> <p>Literature review to examine the impact of self-management education on health outcomes.</p>	<p>Provides a good description of the many forms of education currently being provided (GP-led, nurse-led, pharmacy-based, and multidisciplinary).</p> <p>Sources used in review appear reliable.</p>	<p>No description of methods/approach to literature review.</p>	<p>Importance of education for caregivers in improving independent management of asthma.</p> <p>Focused on primary care.</p> <p>Found improved outcomes using interdisciplinary approach for asthma education.</p>
<p>(Silva et al., 2015)</p> <p>Cross-sectional study aimed at examining the links between coping (via denial or acceptance), disease burden, and QOL in the caregivers of children with asthma. Data collected through questionnaires during health visits.</p>	<p>Reasonable study size: parents of 182 parents of 112 children with asthma.</p> <p>Retrieved a large amount of data with a very thorough analysis (multivariate analyses performed).</p>	<p>Study completed in Portugal; potentially providing different variables that in Canada</p> <p>Cross-sectional design provides data for that particular snapshot of time.</p> <p>Possible selection bias due to convenience sampling, and recruitment taking place in 3 similar centres.</p> <p>Possibly low generalizability due to low variability in asthma severity, and similar socioeconomic status amongst participants (low/medium socioeconomic status).</p>	<p>Found that disease burden is associated with decreased QOL, speculating that measures to ease burden may contribute to improved QOL.</p> <p>Found that caregivers that coped via acceptance (rather than denial) demonstrated higher QOL ($\beta = .29, p = .01$).</p> <p>Affirms that there is increased disease burden on caregivers of younger children due to greater dependence for needs.</p> <p>Does not use PACQLQ as QOL measure, uses WHOQOL.</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Sleath et al., 2011)</p> <p>Cross-sectional study examining child and caregiver involvement in asthma visits.</p>	<p>Appropriate, thorough methodology for data collection; used interviews with tape recording, then coding for data interpretation.</p> <p>Large sample: 333 families, 41 primary care providers.</p> <p>Good variability in demographics of children, caregivers, and providers. Variation in asthma severity.</p>	<p>Providers, caregivers, and children knew they were being audio-recorded, possibly affecting interactions.</p> <p>Convenience sample; possibility that certain populations attend the clinic and would agree to participate in the study.</p> <p>US-based; different health system potentially providing different variables than in Canada (e.g. cost of health care).</p>	<p>Involved primary care practitioners, including NPs (11%).</p> <p>Found that providers do not include caregiver input enough while developing management plan.</p> <p>Only 33% of caregivers asked one or more questions during visits. Providers only asked for caregiver input on the management plan in 10% of the visits recorded.</p> <p>Discusses the importance of communication and collaboration between caregivers and providers, of education, and of individualizing care (e.g. to fit the lifestyle of the family).</p> <p>Recommends providers take steps to support caregiver involvement in decision-making and involvement in visits.</p>


Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Stelmach et al., 2012)</p> <p>9-week cohort study aimed at examining the usefulness of the PACQLQ and whether there is correlation between caregiver QOL, child QOL and asthma control.</p>	<p>Reasonable sample size: 110 caregiver/child dyads.</p> <p>Consistent measure used throughout (PACQLQ). Measured at multiple points in care (weeks 1, 5, and 9).</p>	<p>Did not provide demographic information, or detailed information on recruitment. Not clear on type of clinic participants were recruited from. Unsure of generalizability.</p> <p>Study completed in Poland, potentially providing different variables then in Canada.</p>	<p>Provided evidence for measuring caregiver QOL using the PACQLQ.</p> <p>Found that PACQLQ may be valuable in indirectly assessing child's asthma control.</p> <p>Significant improvement in PACQLQ score when asthma control was gained (7 point increase in QOL score, $p < .01$)</p>
<p>(Tan et al., 2013)</p> <p>A mixed-method study evaluating the effects of AAPs on caregiver understanding of symptoms, use of medication, and frequency of acute care visits.</p> <p>Involved focus groups to explore the understanding and management of asthma followed by a survey to determine AAP use.</p>	<p>Large sample size recruited from various sites: 169 caregivers from 9 primary care clinics. Varied demographics. Good generalizability.</p>	<p>Study completed in Singapore, however AAPs and asthma treatment and management appeared similar to Canadian standards.</p>	<p>AAP use was associated with greater caregiver understanding of the disease and improved use of medications during exacerbation (adjusted odds ratio = .53-5.71; all p values in these domains $< .061$, most $< .01$).</p> <p>Describes AAPs being of best use alongside education.</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Trzcieniecka-Green et al., 2015)</p> <p>Non-experimental, cross-sectional study examining QOL in parents of children with asthma. Compared 2 groups: (1) Children with a new diagnosis of asthma (< 3 months), and (2) children diagnosed at least 1 year prior.</p>	<p>Used consistent methods of data collection: PACQLQ and Satisfaction with Life Scale (SWLS).</p>	<p>Study completed in Poland; potentially providing different variables than in Canada.</p> <p>Limited statistically significant results. Did not report many statistical values in article.</p> <p>Small sample size: 60 parents of children with asthma.</p> <p>All participants were recruited from one health centre, possibly limiting generalizability and increasing risk of selection bias.</p>	<p>PACQLQ used as measure of caregiver QOL. Consistent, slight (not statistically significant, values not reported) increase in QOL was found when the diagnosis was > 1 year, possibly indicating that caregivers adapt to disease burden.</p> <p>Found that life satisfaction was rated better in the caregivers of children diagnosed at least one year prior, compared to those with a new diagnosis in caregivers ages 20-30 years old (chi-square = 5.17; $p < .05$).</p>

Article / Study Design and Overview	Strengths	Limitations	Utility/Important Findings
<p>(Walker et al., 2008)</p> <p>Longitudinal study examining the effects of an asthma education intervention. Intervention providing devices and literature, and participation in asthma workshops.</p>	<p>Compared intervention group to control group. Participants were randomized into groups.</p> <p>Reasonable sample size: 221 children with asthma and their families.</p> <p>QOL measured with consistent tool (PAQLQ for children, PACQLQ for caregivers).</p> <p>Thorough data analysis: analyzes QOL in relation to both the variables and the intervention. Considers the different elements of the PACQLQ (e.g. emotional, activity), not just overall QOL.</p>	<p>US-based; different health system potentially providing different variables than in Canada.</p> <p>Participants were all from one school, possibly contributing to selection bias.</p> <p>Limited variability in demographics may decrease generalizability; most caregivers were white, had a high school education, and most families were rural and middle-income.</p> <p>Reproducibility: findings around educational interventions contrast other studies (most have found a relationship between education and QOL).</p> <p>Possible recall bias: long period between QOL questionnaires (10 months).</p>	<p>PACQLQ scores were highly correlated with missed work days and asthma severity. Fewer missed days of work was associated with higher mean QOL scores ($p < .001$). High asthma severity was associated with decreased emotional QOL ($p = .009$) and activity QOL ($p = .03$).</p> <p>No statistically significant findings that the particular educational intervention had any effect on caregiver QOL.</p> <p>Recommendations that interventions and education focus on decreasing asthma severity and improving control in order to improve caregiver QOL.</p>

Appendix D


Asthma Action Plan Example²



Asthma Action Plan for Children age 1-5

Name: _____ Date: _____


Practitioner: _____ Contact #: _____

GREEN ZONE - GOOD | Controlled Asthma



☐ NO COUGH or WHEEZE with play, crying, or in the night
☐ Not missing daycare/preschool
☐ Parents are not missing work


WHAT SHOULD I DO?
CONTROLLER - REDUCES AIRWAY SWELLING

MEDICINE:	PUFF/DOSE	TIMES/DAY



Take **EVERDAY** to prevent asthma symptoms.




YELLOW ZONE - CAUTION | Take Action - Flare Up


☐ Cough especially while sleeping
☐ Wheeze or shortness of breath

☐ Getting a "cold"
☐ Symptoms with play or normal activity

WHAT SHOULD I DO?
KEEP TAKING CONTROLLER - REDUCES AIRWAY SWELLING


MEDICINE:	PUFF/DOSE	TIMES/DAY




USE RELIEVER AS NEEDED - OPENS TIGHT AIRWAYS QUICKLY

MEDICINE:	PUFF/DOSE	TIMES/DAY
		Up to every 4 hours as needed


If reliever medicine is needed every 4 hours or if asthma symptoms are not improving after see your practitioner.



RED ZONE - DANGER | Take Action - Get Help


WHAT SHOULD I DO?
CALL 911 or GO TO THE NEAREST EMERGENCY DEPARTMENT IMMEDIATELY

Give 5 puffs of reliever medicine using spacer (with mask) every 20 minutes on the way to hospital or while waiting for help. Repeat if no improvement.



Please review this Action Plan with your doctor **twice a year**, within 3 months of a medication change or within 2 weeks following an emergency department or hospital visit. For BC Health Link Dial 8-1-1.

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Goals for asthma treatment

Triggers

Things that irritate (or bother) your child's airways are called triggers. Triggers make asthma flare up. Circle the triggers that make your child's asthma worse:



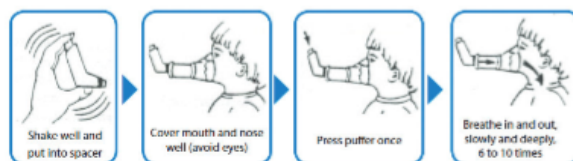
EXERCISE _____

OTHER TRIGGERS _____

Regular play and exercise is good for your child's health. If your child has symptoms with exercise, it may mean that his/her asthma is not well controlled; see your action plan or see your practitioner or asthma clinic for advice.

Knowing and using your child's device

- ☐ Your child should use a Spacer with Mask and a Metered Dose Inhaler (Puffer)



Suggested age: infant and child less than 5 years of age (or anyone unable to use a spacer with mouth-piece)

- If another puff is prescribed, wait 30 seconds
- Rinse mouth and wash face after use of preventer/controller

- ☐ Your child should use a Spacer with Mouthpiece and Metered Dose Inhaler (Puffer)



Suggested age: 5 years and up, if they can follow instructions to breath deeply

- If another puff is prescribed, wait 30 seconds
- Rinse mouth and wash face after use of preventer/controller
- If can't hold breath, can also breathe in and out 6-10 times

For BC Health Link Dial 8-1-1. You can talk to a nurse 24/7 and a pharmacist is available 5-9 pm daily.
Translation interpreters available in 144 different languages.

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